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ABSTRACT

The paper outlines the educational objectives of a course offered at the 1982 meeting of the American Academy on Cerebral Palsy and Developmental Medicine. The course addresses policy changes and trends in publically financed services to developmentally disabled persons. Topics covered in the outline are a continuum of care; historical developments of major federal programs; generic and specialized services, entitlement to services; federal government growth; the intergovernmentalized system; the Reagan Administration 1981 agenda; 1981 congressional decisions; 1982 Regan Administration proposals (including federalizing of Medicaid and terminating 44 federal programs); 1982 congressional climate; recent significant Supreme Court decisions (including Southeastern College vs. Davis and Pennhurst State School and Hospital, et al. vs. Halderman, et al.); and 1982 pending public policy issues (such as federal commitment to P.L. 94-142, the Education for All Handicapped Children Act). A final section lists questions yet to be answered on such topics as uniform definitions of chronic disabilities and the realignment of a continuum of care. (CL)

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ANALYSIS

Volume Eleven Number Four

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CHANGING POLICIES AND PROGRAM TRENDS IN PUBLICLY FINANCED SERVICES TO THE DEVELOPMENTALLY DISABLED

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INTRODUCTION

This paper is an outline of the major components of an instructional course offered at the 1982 annual meeting of the American Academy on Cerebral Palsy and Developmental Medicine. The course educational objectives are:

1) To impress upon practitioners of direct services the significance of government financing of services to persons with cerebral palsy and related conditions.

2) To assist program administrators to adjust to changes in governmental funding of services to persons with disabilities.

3) To orient administrators, practitioners, and others to the justification and motivation of U.S. policy makers in changing existing financial arrangements.

4) To identify the response of U.S. constituencies and special interest groups to proposed public policy changes and to suggest ways in which administrators, practitioners, and others may become directly involved in the public policy process.

5) To compare the governmental climate of accepting responsibility for persons with disabilities between the United States and Canada.

6) To encourage course participants to share with one another their recent experiences in working with agencies of the government on behalf of persons with disabilities.

This outline is restricted to the United States federal government program structure and public policies. The Canadian experience is presented in a second set of materials by Stanley M. Hudecki, M.D., Member of Parliament-Hamilton West.

A CONTINUUM OF CARE

1) In 1979, an estimated $10.8 billion in federal, state, and local government expenditures were allocated to roughly 1.7 million mentally retarded and developmentally disabled persons with $4.3 billion of this federal government expenditures. (1)

2) According to Copeland and Iverson (1), historically, only the state institutions have enjoyed a stable professional hierarchy, uncomplicated funding, and the confidence of state agencies and legislative bodies. (1)

3) In the developmental disabilities field over the past two decades, a number of programmatic philosophies have developed that challenge the institutional model of service. Such concepts as the developmental model, least restrictive alternative, integration of the disabled with the non-disabled, community placement, and small and scattered site housing have been alternatives to the institutional approach.

4) Combining with these new programmatic theories was a civil rights movement that attacked the frequently overcrowded and inhumane treatment environment of many state institutions. Concepts such as warehousing, inactive treatment, abuse and neglect, individualization, and due process have challenged the level of services in state institutions.

5) Today, a dual system of community and institutional services exists. Few states have developed effective strategies that link the two systems programmatically and financially.

6) According to Braddock (2), the present ratio of funding between institutional and community services sectors is 5:1. To Braddock, a reasonable fiscal goal in every state by 1985-1988 is funding parity between the two sectors.

7) A "continuum of care" is a set of care opportunities for a group of persons characterized by similar or identical problems that are ordered according to their intensity, their cost, and their restrictiveness of environment. A continuum of care system assumes the separation of program reporting for each long-term care subpopulation; unfortunately, today, few reports exist and those that are operational are generally categorized by type of vendor not type of recipient. (1)

8) Continuum of care systems can not be designed until:

   a) There are consistent federal, state, and local program and financing policies.
   b) There are financial incentives in the preferred direction of community placement.
   c) There is a case management and centralized placement agency.
   d) There are services appropriate to the placement location.
   e) There are distinctly defined levels of care by placement location.
   f) There are interagency coordination agreements, including both public and private agencies, in place.
   g) There is a centralized data system including data on costs and cost-effective program analysis.
   h) There is a unified budgeting and planning organization.
   i) There is consistent multi-program eligibility.
   j) There is a capability of determining and documenting behavioral and activities of daily living (ADL) skills and their relationship to residential placements and program progressions.
   k) There is a standardized approach to client assessments.

9) The professed public policy goal and objective of many national developmental disability organizations, including UCPA, is the promotion of community based services using the philosophy of the least restrictive alternative. The remainder of this paper attempts to identify the role the federal government has played in promoting a continuum of care.

HISTORICAL DEVELOPMENT OF MAJOR FEDERAL PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

In many ways, federal government programs have evolved based on documented human need and special interest group lobbying. Because of the variety of needs and interest groups, a large number of generally uncoordinated and self-contained programs have evolved over time. In many ways, these programs contradict the essential items of continuum of care systems.

1)a) 1918, Vocational Rehabilitation Act for disabled veterans.

   b) 1920, "National Civilian Vocational Rehabilitation Act of 1920."

2) 1933, "Federal Emergency Relief Act;" cash payments for poor individuals.

3) 1935, "Social Security Act."

   a) Cash payments to families with dependent children, old age assistance, and survivors assistance.

   b) Established the Maternal and Child Health and Crippled Children Services Programs.

4) 1950, Social Security Amendments; established a separate federal grant-in-aid program to "permanently and totally disabled" adults.

5) 1957, Social Security Amendments; Disability Insurance program established.

6) 1962, Social Security Act Amendments; Social Services for public assistance recipients authorized.

7) 1963, "Maternal and Child Health and Mental Retardation Planning Amendments of 1963." P.L. 88-156, October 24, 1963, targeted resources on the mentally retarded and established a state planning mechanism for persons with mental retardation.

8) 1963, "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963." P.L. 88-164, October 31, 1963, established community mental health centers and authorized the construction of mental retardation centers and university affiliated facilities for the mentally retarded.

9) 1963, "Vocational Education Act of 1963." P.L. 88-210.

10) 1964, "Urban Mass Transportation Act of 1964." P.L. 88-365 established federal grants for mass transit.

11) 1965, "Elementary and Secondary Education Act of 1965." P.L. 89-10, April 11, 1965.

12) 1965, "Social Security Amendments of 1965." P.L. 89-97, July 30, 1965, established the Medicaid and Medicare programs.

13) 1965, "Elementary and Secondary Education Amendments." P.L. 89-313, November 1, 1965, authorized federal funds to state owned and operated schools for the handicapped (institutions).

14) 1966, "Comprehensive Health Planning and Public Health Services Amendments of 1966." P.L. 89-749, November 3, 1966, established health planning agencies in the states.

15) 1967, "Mental Retardation Amendments of 1967." P.L. 90-170, December 4, 1967 authorized partial payment of the cost of professional and technical personnel in mental retardation facilities.

16) 1968, "Architectural Barriers Act of 1968." P.L. 90-480, August 12, 1968, required federally funded buildings to be accessible to the disabled.

17) 1968, "Handicapped Children's Early Education Assistance Act;" P.L. 90-538, September 30, 1968, authorized federal grants to the states for educating handicapped children.

18) 1968, "Vocational Education Amendments of 1968." P.L. 90-576, October 16, 1968, required 10% state set-aside for the handicapped under the Voc Ed program.

October, 1968: UCPA Establishes
A Washington Office

19) 1970, "Developmental Disabilities Services and Facilities Construction Act of 1970." P.L. 91-517, October 30, 1970, drastically amended the old mental retardation laws. Cerebral palsy was specifically listed as a developmental disability and state planning councils were firmly established.

20) 1971, "Social Security Amendments." P.L. 92-223, December 28, 1971, established the Medicaid Intermediate Care Facility for the Mentally Retarded (and other developmentally disabled) program.

21) 1972, "State and Local Fiscal Assistance Act." P.L. 95-512, October 20, 1972, established the Revenue Sharing program and placed a $2.5 billion ceiling on the Title XX program.

22) 1972, "Social Security and Welfare Reform Amendments of 1972." P.L. 92-602, October 30, 1972, established the Supplemental Security Income (SSI) program.

23) 1973, "Federal Aid Highway Act of 1973." P.L. 93-87, August 13, 1973, required federal mass transit projects to be accessible to the handicapped.

24) 1973, "Rehabilitation Act of 1973." P.L. 93-112, September 26, 1973, revised the VR program to include special emphasis on the severely handicapped, established the Architectural and Transportation Barriers Compliance Board, and authorized Title V civil rights protections, including Section 504 nondiscrimination protections.

25) 1973, "Comprehensive Employment and Training Act of 1973." P.L. 93-203, December 28, 1973, established a consolidated manpower training program.

26) 1974, "Housing and Community Development Act of 1974." P.L. 93-383, August 22, 1974, for the first time targeted federal housing programs for the disabled. Of special note are Section 202 construction and Section 8 rent subsidies programs.

27) 1975, "National Health Planning and Resources Development Act of 1974." P.L. 93-641, January 4, 1975, strengthened health planning agencies.

28) 1975, "Social Services Amendments of 1975," P.L. 93-647, January 4, 1975, consolidated Social Services programs into a new Title XX.

29) 1975, "Developmental Disabilities Assistance and Bill of Rights Act." P.L. 94-103, October 4, 1975, established Protection and Advocacy Systems for the developmentally disabled in every state.

30) 1975, "Education For All Handicapped Children Act of 1975." P.L. 94-142, November 29, 1975, declared that every handicapped child is entitled to a "free, appropriate, public education."

31) 1978, "Comprehensive Employment and Training Act Amendments of 1978." P.L. 95-524, October 27, 1978, specifically included the handicapped within the definition of "economically disadvantaged" and targeted special national attention to the handicapped.

32) 1978, "Housing and Community Development Amendments of 1978." P.L. 95-557, October 31, 1978, established a new Congregate Housing Services Program.

33) 1978, "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978." P.L. 95-602, November 6, 1978, altered the categorical definition of developmental disability to a functionally based one; strengthened consumer composition on State councils; targeted DD funds to the national service priorities of community living arrangements, case management, child development, and non-vocational/social-developmental services; established the Comprehensive Services for Independent Living Program; established the National Institute of Handicapped Research; and authorized community services employment pilot programs.

34) 1980, "Civil Rights of Institutionalized Persons Act." P.L. 96-247, May 23, 1980, gave the U.S. Department of Justice legal standing to protect residents of public institutions from abuse.

35) 1980, "Social Security Disability Amendments of 1980." P.L. 96-265, June 9, 1980, liberalized SSI and Medicaid benefits to encourage work by the severely disabled.

36) 1980, "Adoption Assistance and Child Welfare Act of 1980." P.L. 96-272, June 17, 1980, authorized a new adoption assistance program designed for children with special needs.

37) 1980, "Housing and Community Development Act of 1980." P.L. 96-399, October 8, 1980, amended the HUD Section 202 loan program to allow the purchase of existing housing to be used by the non-elderly handicapped.

GENERIC AND SPECIALIZED SERVICES

In 1962, the President's Panel on Mental Retardation recommended that generic services should be used whenever possible to meet the multifaceted needs of severely disabled persons. Generic services are those services offered to the general public, including the disabled. Specialized services are those offered only to the disabled. This 1962 statement reflected a change in ideology and philosophy which emphasized integration into the mainstream of community life as an appropriate programmatic goal. In 1976, the President's Committee on Mental Retardation declared that "specialized services should be resorted to only when the limits of feasible mainstreaming are reached." (3) (4)

1) Federal Specialized Programs: Dollar Impact

Specialized Program	FY 1972	FY 1980	FY 1982*
(Program, Initial Enactment)		(Federal Appropriations Level)	
Vocational Rehabilitation State grants, (1918, 1920)	$560 million	$817 million	$899 million

1) Federal Specialized Programs: Dollar Impact (cont'd.)

Specialized Program	FY 1972	FY 1980	FY 1982*
Social Security Disability Insurance (SSDI) Program (1957)	4.2 billion	15.066 billion	17.7 billion
Maternal and Child Health and Crippled Childrens Services (1935) (1981)	252.2 million	457.4 million	362 million**
Developmental Disabilities Act (1963 a mr authority, 1970)	45.6 million	62.14 million	62.13 million
Education for All Handicapped Children (early education 1968) (1975)	37.5 million	874 million	969.8 million
Comprehensive Services for Independent Living (1978)	----------	15 million	18.0 million

*As enacted in P.L. 97-35, the Budget Reconciliation Act.
**Consolidated with 6 other programs into a new block grant program.

2) Federal Generic Programs: Dollar Impact

Generic Program	FY 1972	FY 1980	FY 1982*
(Program, Initial Enactment)	(Federal Appropriations Level)		
Aid to the Permanently and Totally Disabled (1950)	$1.2 billion	Incorporated into SSI	
Vocational Education (1963) set-aside for the handicapped (1968)	6.8 million	779 million	632 million
Elementary and Secondary Education Act (April 1965) set-aside for handicapped children (November 1965)	81.9 million	3.116 billion	2.4 billion
Medicaid (1965) ICF/MR (1971)	4.4 billion	13.8 billion	17.4 billion
Medicare (1965)	8.6 billion	24.3 billion	33.7 billion
Supplemental Security Income (SSI) (1972)	---------- (see APTD)	5.653 billion	6.9 billion

2) Federal Generic Programs: Dollar Impact (cont'd.)

Generic Program	FY 1972	FY 1980	FY 1982*
Comprehensive Employment and Training Act (1973) (target on the handicapped, 1978)	-------	6.4 billion	4.2 billion
Section 202 housing development loans (1959, physically handicapped in 1965, and 1974)	-------	830 million	830 million
Congregate Housing Services Program (1978)	-------	10 million	-0-

*As enacted in P.L. 97-35, the Budget Reconciliation Act.

In FY 1982, there were 2.9 million disabled recipients of Medicaid, 3.04 million enrollees and 830,000 recipients of Medicare Part A benefits, 2.771 million enrollees and 1.8 million recipients of Medicare Part B benefits, 2.2 million SSI disabled and blind recipients, and 2.7 million SSDI disabled recipients.

3) 1982 Issues

The fundamental question is how to balance maximum use of generic services while retaining unique and needed specialized services. Questions of eligibility, financing, and administering agency are significant dimensions. To Gettings (4), generic services don't operate optimally thus the arguments for specialized services arise. Cutbacks in generic services program increase the arguments for specialized services. Fiscal restraints result in greater competition for scarce public resources. Four particular problems have been identified by Gettings: (a) Access to services, (b) Lack of unique needs response, (c) Termination of services because of prolonged outcome measures, and (d) Individualization exceedingly difficult because of the size and complexity of programs.

ENTITLEMENT TO SERVICES

1) Most of the "generic" programs discussed above are based on an "entitlement" to eligibility and benefits.

2) To Grumet (5), "Once an individual becomes entitled to benefits from such a program, he or she acquires a 'property interest' in continuing to receive these benefits. Such interests, along with life and liberty, are protected by the due process clause of the United States Constitution and cannot be withdrawn without the protections of due process."

3) Laski defines entitlement to service as existing when two conditions are met: (a) there exists a definable duty on the part of ascertainable service providers to give service to a particular person and (b) the person who is the beneficiary of the duty has legal remedy which they can use to enforce performance of the duty or collect damages for failure to perform. Without both conditions, the duty and the capacity to enforce the duty, there is no entitlement. (6)

4) Grumet documents that courts have tended to focus on three factors in deciding what constitutes "due process" when benefits are withdrawn:

   a) The nature of the affected interest: is the government action a direct or indirect impact on a particular individual? Is the individual a direct target of the action or a third party?

   b) The impact of the decision on the beneficiary.

   c) The danger of risk or error.

5) O'Bannon vs. Town Court, 1980: The U.S. Supreme Court held that Medicare-Medicaid nursing home residents do not have a due process right to participate in proceedings to terminate the nursing home from program participation because they are a third party. As Grument summarized, "The fact that the provider is furnishing services to which the recipient is entitled under a government benefit program is irrelevant for due process purposes. The recipient's interest is indirect to the property interest of the contractor."

6) Examples of due process rights include:

   a) Education. P.L. 94-142 requires state and local school districts to provide procedures for insuring that handicapped children and their parents or guardians are guaranteed procedural safeguards in decisions regarding identification, evaluation, and educational placement of handicapped children.

   b) Social Security. The Supplemental Security Income Program establishes detailed criteria permitting the applicant and recipient to question and challenge decisions regarding his eligibility, payment levels, etc.

FEDERAL GOVERNMENT GROWTH

1) 1960, there were 132 federal grant programs totalling $7.0 billion which constituted 1.4% of GNP. In 1964, 75% of federal assistance to the states was focused on highways, aid to the aged, AFDC, and employment security. By 1980, there were 540 federal grant programs totalling $89 billion which constituted 3.3% of GNP. (7)

2) 1965, federal grant direct aid to local governments was $2.2 billion. By 1978, federal grant direct aid to local governments was $19.4 billion, a 782% increase. In 1960, only 8% of federal aid went directly to local government. In 1980, 25% of federal grant aid went directly to 63,000 subnational governments. (7)

   a) 1965, Title I, Elementary and Secondary Education Act (ESEA), brought the federal government into direct contact with almost every school district.

   b) 1972, General Revenue Sharing (GRS), brought the federal government into direct contact with 38,000 units of local government.

3) Federal Aid as a Percent of State and Local Government Receipts

   The Advisory Commission on Intergovernmental Relations (ACIR) has made the following projections based on the Administration's budget requests:

   a) Peak year-1978-31.7%

   b) 1979-30.9%

c) 1980-31.7%-matched the peak year

d) 1981-29.5%

e) 1982-24.3%

4) 1980 UCPA Perspective: Major problems facing programs serving the disabled were:

a) lack of adequate funding levels and

b) failure to fully implement statutory objectives (compliance).

5) 1930 ACIR Perspective: The nation faced a "delusion of nationalization" and an "illusion of a national response" with 540 separate categorical programs, each with inadequate budgets. (8)

a) Example, in 1978, Congress established a "Comprehensive Services for Independent Living Program" which has always operated as a federally administered special project authority of $15-to-$18 million.

b) State and local governments were faced with the Four C's: conditions, cash, cut-off of funds threat, and court cases.

6) 1980 NACo (National Association of Counties) Perspective: Intergovernmental relations can be characterized by "mandate madness" whereby there are 59 "cross cutting" grant requirements which include 9 national policy requirements, 12 nondiscrimination requirements, 5 environmental protection mandates, 4 labor and procurement standards, 3 public employees standards, 4 access to government information provisions, and 1 real property location requirement. (9)

a) In 1980, there were an average 60 regulations for each federal grant application. (10)

b) As of 1981, there are 437 pages of law and 1200 pages of regulation for 100 programs in health and social services. The federal government administered about 5,800 separate grants at 24,000 grant sites. Excluding time spent prior to award, each year over seven million person hours of state, local, and community effort are used in filling out federally required reports. (11)

7) George Will 1981 Observations:

a) "Political demands and fiscal capabilities are radically unsynchronized: the government is unable to finance the services that the public is unwilling to forgo."

b) The Deary Truth: "The nation has made many promises to many groups on the basis of unrealized and, for the foreseeable future, unrealized expectations of economic and revenue growth."

THE INTERGOVERNMENTALIZED SYSTEM

Copeland and Iverson (12) reported that almost all federally funded programs in human services require states to carry out a myriad of functions which are used punitively to "minimize Federal financial participation in funding programs" such as:

1) Develop a state service plan based on categorical need assessment;

2) Report inputs and outputs for each program on at least a quarterly basis;

3) Meet financial audit and different audit requirements for each program;

4) Establish client eligibility requirements as a prerequisite for delivery of services;

5) Meet federal specifications for kind of agency or organization which could provide services; and

6) Establish and meet professional preferences as well as accreditation standards as specified by the federal program.

THE REAGAN ADMINISTRATION
1981 AGENDA

1) The major goal of the Reagan Administration is "full and vigorous recovery of the American economy." Four policies form the basis of a comprehensive plan for economic recovery. They are: (1) substantial reductions in the growth of federal expenditures; (2) significant reduction in federal tax rates; (3) prudent relief of inappropriate federal regulatory burdens; and (4) a monetary policy on the part of the independent Federal Reserve consistent with the above policies. (11)

2) To Walker (8), Reagan = d^3 (d to the third power); devolution, deregulation, and deinstitutionalization of government (dismantling the bureaucracy).

3) It is important to recognize the ideological emphasis of the Reagan Administration in attempting to understand their public policy proposals. (13) (14)

   a) In April, 1981, in a speech to the National Association of Counties, President Reagan stated "I have a dream of my own. I think block grants are only the intermediate steps. I dream of the day when the Federal Government can substitute for those the turning back to local and state governments of the tax sources we ourselves have pre-empted here at the Federal level so that you would have those tax sources."

   b) Robert Carleson, Special Assistant to the President for Domestic Policy Development also continues to declare that "block grants are merely an interim step" in the President's plan to turn all human service programs over to the states. At a meeting of the National Health Policy Forum, Carleson further stated that "block grants are a step toward total withdrawal of the Federal Government from education, health and social services programs which the Administration believes are properly the responsibility of state and local governments."

   c) David Stockman, Director, Office of Management and Budget (OMB), has declared that "I don't believe that there is any entitlement, any basic right to legal services or any other kind of services....The idea of... (services) financed by the government as a matter of basic right is wrong. We challenge that. We reject that notion."

4) <u>1981 Legislative Program</u> (13) (14)

   a) 83 categoricals into 6 blocks: health services, preventive health services, social services, energy and emergency asst., special ed needs, state ed functions. Plus other consolidations, such as CD.

b) Disability programs: VR, IL, DD, P.L. 94-142, and P.L. 89-313 would be terminated and their functions consolidated into block grants.

c) $61 billion reduction in human services proposed (from FY '81 to FY '82) (includes spring '81 and Sept. '81 proposals).

d) Walker: "The Administration's proposals for restructuring the grant system, although mostly described as block grants, really fit the revenue sharing model....Questions legitimately may be raised regarding the national purposes and pattern of accountability reflected in" the P.L. 97-35 block grants.

5) The Administration's block grant proposals contained certain common features demonstrating a general approach. (13) (14) These features included:

a) Reduce federal funds 25% in FY 1982 below FY 1981 levels;

b) Distribute remaining funds among the states based on the proportions of federal money received in FY 1981;

c) Allow governors to shift up to 10% between block grants (education excluded);

d) Abolish state matching and maintenance of effort requirements; and

e) Hold appropriations levels for FY 1983, '84, and '85 to the same level as FY 1982.

1981 CONGRESSIONAL DECISIONS (13) (14)

1) Walker's September '81 Assessment: "In this struggle between the array of categorical program interests and the consolidationists, the results were pretty much a draw with both sides scoring some points and losing others."

2) P.L. 97-35, the "Omnibus Reconciliation Act of 1981," enacted in July, 1981 made substantive changes in over 250 existing federal laws.

3) P.L. 97-35 merged 57 of the federal government's then existing 540 categorical grants programs into 9 block grants.

4) The P.L. 97-35 authorized block grants expand the state government role and reduce both the federal and local government role in the overall federal grant system.

5) P.L. 97-35 eliminated 62 of the federal government's then existing 540 categorical grants programs.

6) Through the combination of P.L. 97-35 and P.L. 97-92, federal expenditures from FY 1981 to FY 1982 were reduced by $39 billion and roughly 66% of this reduction came in grants to state and local governments.

7) P.L. 97-34, the "Economic Recovery Tax Act of 1981," further reduced state government tax revenues, estimated to be $2.3 billion in FY 1982.

8) In P.L. 97-35, Congress refused to block grant the Developmental Disabilities, Vocational Rehabilitation, Independent Living, and P.L. 94-142 "Education for All Handicapped Children Act" programs.

9) In both P.L. 97-35 and P.L. 97-92, Congress generally retained funding for the above cited categorical programs for persons with disabilities at FY 1981 levels.

10) In both P.L. 97-35 and P.L. 97-92, the Title XX Social Services program was reduced by $500 million and the Maternal and Child Health program was reduced by $100.1 million.

11) By P.L. 97-35 and P.L. 97-92, the 7 block grants in health and human services operated from 75 to 90% of their FY 1981 funding levels.

12) In P.L. 97-35, Congress rejected the Administration's arbitrary cap on Medicaid expenditures, altered the matching formula to require greater state investment, and enacted the "waiver" program to allow non-institutional community based services as an alternative to institutionalization. The waiver program was a major program liberalization which had been a UCPA legislative priority for three years.

1982 REAGAN ADMINISTRATION PROPOSALS (14)

1) Immediately following P.L. 97-35:

   a) President: We will go back to Congress, go back, and go back again until our proposals are enacted.

   b) Carleson: We will operate block grants as revenue sharing.

   c) Harold Steinberg, OMB Associate Director for Management: "There is a point of view in the Administration that these block grant programs are not programs but fiscal transfer mechanisms."

2) November 1981 Press Interview with President Reagan:

   a) Question: "Do you think it's at all the responsibility of the national government to redistribute the resources between the states that are relatively well off and the states that are not?"

   b) Reply: "No, I think that is up to the states. My first reaction to that is, this is one of the--built-in guarantee of freedom is our federalism, that makes us so unique, and that is that the right of the citizen to vote with his feet. If the state is badly managed the people will either do one of two things: they will either use their power at the polls to redress that, or they'll go someplace else."

   c) OMB Deputy Director Edwin Harper (now Chief Domestic Advisor having replaced Martin Anderson): "The net impact of the CDBG has been to shift, not increase, economic development." Since redistribution and equalizing resources is not a legitimate federal role, then eliminate the program.

3) President has proposed a "New Federalism Swap" whereby Medicaid will be totally federalized and AFDC and Food Stamps will become total state responsibilities.

   a) Representatives of state and local government and the White House have negotiated for months without reaching agreement.

   b) The White House has slightly modified the proposal whereby Medicaid acute care will be federalized, Medicaid long term care will be block granted with a financial ceiling, and Food Stamps will be federalized.

c) August, 1982: Vermont Governor Richard A. Snelling, out going chairman of the National Governors Association: "Substantial philosophical differences remain between the governors and Administration." (15)

1) NGA proposes federalization of AFDC.

2) NGA opposes retaining the wide variations in eligibility standards and benefit payments which presently exist in Medicaid.

3) NGA proposes federalized Medicaid eligibility for the medically needy. (16)

4) Refer to upcoming discussion of "Turnback" Proposal.

5) The National Conference of State Legislatures (NCSL) and National Association of Counties (NACo) share the NGA approach. (17) (18)

4) President has proposed a "New Federalism Turnback" whereby 44 federal programs (actually 125 programs in 1981 terms) would be terminated and given to the states.

a) Included in terminated programs are Vocational Rehabilitation, Independent Living, Maternal and Child Health, and Title XX Social Services.

b) The President proposes a trust fund to operate as "no-strings revenue sharing" in 1984-1987. In 1988, a 25% decline in the trust fund would begin with termination of the trust fund in 1991.

1) Starting in 1984, there would be absolutely no federal regulation of the turnbacked programs.

2) In 1991, certain federal excise taxes over alcohol, tobacco, telephone, and motor fuel would be turned over to the states.

3) NGA opposes the trust fund as proposed by the President as "unrealistic" and "unjust" financial burdens on the states. NGA proposes a permanent federal safety net supplemental assistance fund for the states. (16) NGA argues that "the Administration is trying to shift disproportionate costs to the states." (15)

4) NCSL and NACo share the NGA concerns. They desire a permanent federal trust fund to respond to inequities and disparities between states. They are concerned with the type of federal tax which will finance the trust fund. They wish to guarantee that the funding levels be adequate to finance turnbacked programs. NACo and NCSL/NGA differ on how to structure a "pass through" mechanism to local governments. (17) (18)

5) The President has proposed more block grants including:

a) P.L. 94-142, preschool incentive, P.L. 89-313 into a state special education block grant.

b) All Education of the Handicapped Act discretionary programs into a special purpose block grant.

c) Vocational Education and Adult Ed consolidation.

d) All rehabilitation programs consolidation.

e) Maternal and Child Health (MCH) and Women, Infant, and Children (WIC) feeding program consolidation.

f) Child welfare services block grant.

1982 CONGRESSIONAL CLIMATE

1) Alice M. Rivlin, Director, Congressional Budget Office, March 16, 1982 testimony to Senate Committee on Governmental Affairs: "Changing circumstances and perceptions have also led increasing numbers of persons to question the whole division of responsibility between the federal government and states and localities." (14)

2) NGA: "There is a logical division of labor between the national and state and local governments which should be reflected in individual domestic policy decisions at the state and federal levels." (14)

   a) Gov. Carey (NY): Reagan program resembles someone walking out of a restaurant without paying the bill and claiming that this reduces the price of food.

   b) Gov. Hunt (NC): "The nation's governors are finding that trying to debate "new federalism" this year is like trying to rearrange the furniture while the house is burning down."

   c) Gov. Snelling (VT): "I think change is inevitable because of the financial restraints now being imposed upon the federal government and the Congress. They have no choice but to sort out responsibilities and costs."

3) Senator Pete V. Domenici (NM), Chairman, Senate Budget Committee and member of the Presidential Advisory Committee on Federalism; April 21 assessment: "Unfortunately, White House staff members and representatives of state and local governments seem to have reached a deadlock in the negotiations. Why? In my opinion, both the coalition of state and local officials and the White House staff have been too inflexible in these critical negotiations." (14)

4) Michael DelGiudice (19):

   a) "Nearly all congressional observers admit that the Administration's program is doomed in Congress unless Reagan is able to get agreement with the states and present a unified package to Congress."

   b) Reagan's proposal simply is not ready for enactment. It contains too many elements of uncertainty, unsupportable analyses, imprecise calculations of effects, and above all does not take into account experience with the transfer in 1981."

5) The President's New Federalism proposal will not be enacted by the 97th Congress. However, the climate and demand for change is strong and "sorting-out" will be a major agenda for the 98th Congress.

RECENT AND SIGNIFICANT SUPREME COURT DECISIONS

During the past few years, the U.S. Supreme Court has issued interpretations regarding the scope of several federal laws impacting on persons with disabilities. Several of these follow.

1) June 11, 1979, Southeastern College vs. Davis: In the Court's first consideration of Section 504 of the "Rehabilitation Act of 1973," the Court declared there were limitations to accommodation responsibilities. The Court reinforced the legality of and need for Section 504, repeated the obligation of federal fund recipients to accommodate to the disabled, and emphasized that accommodation must be reasonable. (20)

   a) The case is narrowly focused. It is concerned with a highly specialized professional/clinical training program which involves the treatment of patients. The Court was fundamentally concerned that the technical/clinical standards of training not be diminished and that the safety of patients must be protected.

   b) The case centered on a practical nurse who has a serious hearing disability who sought admission to a registered nurse training program.

2) April 20, 1981, Pennhurst State School and Hospital, et. Al. vs Halderman, et. Al: The Court concluded that the so-called "Bill of Rights," Section 6010 of the 1975 DD Act, "does not create in favor of the mentally retarded any substantive rights to 'appropriate treatment' in the 'least restrictive' environment." To the Court, Section 6010 "represent general statements of federal policy, not newly created legal duties." (21)

   a) The Court agreed with the lower court observation: "Its findings of fact are undisputed: Conditions at Pennhurst are not only dangerous, with the residents often physically abused or drugged by staff members, but inadequate for the 'habilitation' of the retarded. Indeed, the court found that the physical, intellectual, and emotional skills of some residents have deteriorated at Pennhurst."

   b) "Noticeably absent from 6010 is any language suggesting that 6010 is a 'condition' for the receipt of federal funding under the Act."

   c) "Legislation enacted pursuant to the Spending Power is much in the nature of a contract: in return for federal funds, the States agree to comply with federally imposed conditions. The legitimacy of Congress' power to legislate under the Spending Power thus rests on whether the State voluntarily and knowingly accepts the terms of the 'contract.' There can, of course, be no knowing acceptance if a State is unaware of the conditions or is unable to ascertain what is expected of it. Accordingly, if Congress intends to impose a condition on the grant of federal moneys, it must do so unambiguously."

3) June 28, 1982, Board of Education of the Hendrick Hudson Central School District, et al vs. Amy Rowley, et al: In the Court's first interpretation of P.L. 94-142, the Court ruled that P.L. 94-142 did not require the school district to provide a full-time sign-language interpreter for Amy Rowley. As Barbara Radway has observed, "It is extremely important to recognize and understand that the implications of the ruling and its application in other factual situations remain unclear, and that in other cases, the decision may prove less restrictive than initially appears." (22)

   a) Amy Rowley has minimal residual hearing, is an excellent lip reader, has had a number of special accommodations to her disability from local school officials, and performs better than the average non-disabled child in her class.

   b) Amy's parents claimed that a sign language interpreter was required under P.L. 94-142's requirement for a "free appropriate public education."

c) The Court rejected the Rowley's contention by finding: "If personalized instruction is being provided with sufficient supportive services to permit the child to benefit from the instruction, and the other items on the definitional checklist are satisfied, the child is receiving a 'free appropriate public education' as defined by the Act."

d) The Court reinforced the Act's intention to make public education available to handicapped children using the individualized education plan procedure and due process rights provisions. However, the Court declared that the Act did not establish any substantive standard prescribing the level of education to be accorded handicapped children. Realizing mere access to public education is insufficient, the Court stated that some educational benefit be conferred upon handicapped children. Application of an "educational benefit" standard presents a difficult problem.

1982 PENDING PUBLIC POLICY ISSUES

The single most time consuming activity of the Congress (and thus the UCPA Washington office) is the federal government's budget and annual appropriations measures. A second significant and ongoing area is the debate, negotiation, and consideration of the President's "New Federalism" initiative. Other fall 1982 issues include the following:

1) Federal Commitment to P.L. 94-142, "Education for All Handicapped Children Act"

a) As background, Congress rejected the Administration's 1981 proposal to terminate P.L. 94-142 and block grant it with other elementary and secondary education programs, 1982 proposal to terminate P.L. 94-142 and block grant it with other education for the handicapped programs, and 1981 and 1982 proposals to substantially reduce federal appropriations for these activities.

b) In February 1982, 59 U.S. Senators and 285 U.S. Representatives sent President Reagan an open letter calling upon him to support the substance and funding of P.L. 94-142.

c) August 4, 1982, Department of Education (ED) proposed amendments to the existing rules governing P.L. 94-142. Four areas are of foremost concern to UCPA:

1) Reducing parental involvement and consent in the development of their child's "individual education plan," IEP.

2) Placing limits on "related services" such as physical, occupational, and speech therapy.

3) Transferring certain financial responsibilities from the education agencies and to the parents.

4) Deleting most of the provisions related to placements in the "least restrictive environment," LRE.

d) August 10, the Senate voted 93-4 to express its concern with the proposed regulations and its continued commitment to P.L. 94-142.

e) September 8, ED Secretary Terrel Bell publicly declared that the Administration might "pull back" for "further study" four areas of proposed regs:

1) Parental consent and involvement,

2) Timeline and deadline terminations,

3) Placement and LRE, and

4) Medically related services.

f) November 2 (unless extended) is the deadline for comments to Dr. Edward Sontag, Director, Office of Special Education, ED, 400 Maryland Avenue, S.W., Room 4000, Donohoe Building, Washington, D.C. 20202.

2) Social Security Disability Insurance Case Reviews

a) 1981-1982, the Social Security Administration (SSA) launched an initiative termed "Continuing Disability Investigations," CDIs.

b) Of the 2.7 million SSDI beneficiaries, in 1981-1982, to date, 157,980 persons have been dropped from the rolls. Twenty-nine percent (29%) of these were mentally disabled.

c) CDIs were required by P.L. 96-265 (1980) because of politican and economist alarm at the rate of SSDI case increase and its accompanying budget implications However, by 1981, before the CDIs, the percentage of workers on SSDI was the lowest in the history of program and the program was actuarially sound.

d) Persons are eligible for SSDI and SSI if they have a "medically determinable" disability which prohibits them from engaging in "substantial gainful activities," SGA. SGA is the performance of significant physical or mental duties or a combination of both, productive in nature, for renumeration or profit.

e) John Trollinger of SSA: "You must be unable to do any kind of work. It doesn't matter that you don't have any experience or if there aren't any jobs there."

1) Reagan Administration has used a stricter application of the SGA standard.

2) Result: many persons with little education, few skills, some impairment, who have been on the rolls for years are abruptly informed by computerized letter that they are being cut.

3) Appeals take 9-12 months; 67% of the cases appealed have reversed SSA termination decisions by Administrative Law Judges (ALJ). The ALJs are now working with a record high backlog of 140,000 cases.

f) Consortium Concerned with the Developmentally Disabled (CCDD), which includes UCPA, is seeking three emergency legislative provisions in 1982:

1) Prevent SSA from terminating benefits for recipients whose disabling condition has not improved.

2) Continue benefits until a decision is reached by an ALJ.

3) Reduce the number of cases being reviewed to ensure proper and careful case review.

3) Government Reform: The Administration has proposed legislation which would establish uniform administration requirements for all block grants, would omit public participation in rule making, would prohibit future intergovernmental programs by requiring 100% federal funding of any newly authorized program involving state or local government, and would arbitrarily limit the growth of the federal budget. The CCDD is actively working to ensure full public participation on an equal basis with state and local government in all federally assisted programs and to limit any arbitrary mechanisms which would permanently restrict the federal government's ability to finance domestic services.

4) Housing Legislation: Bills are pending (H.R. 6296 and S. 2607) to continue both the HUD Section 202 loan program and the Congregate Housing Services Program. The House bill would continue the Section 8 rent subsidy program while the Senate bill endorses the Administration's proposal to terminate Section 8 and replace it with a housing voucher system.

5) Employment Legislation: The House and Senate have each passed legislation (H.R. 5320, S. 2036) to replace the expiring Comprehensive Employment and Training Act (CETA). Both bills target eligibility to individuals with handicaps who individuall, meet income test requirements but whose family income does not qualify as "economically disadvantaged."

A CONTINUUM OF CARE?

The advocacy of federal policies which promote a "continuum" of care will be greatly influcenced and affected by the "New Federalism" initiative which centers around program "swaps," "turnback" of programs, "devolution" of authorities, and "sorting-out" responsibilities. Additionally, the level of financial assistance will exert great influence on the establishment and operation of the continuum. Just when the disability first appeared to develop the experience, organization, and sophistication to address the appropriate mix of generic and specialized services and move toward the operationalization of a continuum of care, federal budgets are devastated and the legitimacy of the federal role is questioned. Many questions remain to be answered.

1) Sorting-Out Criteria: Alice Rivlin, Director, Congressional Budget Office (23) has observed that two general criteria are likely to be used in determining what the federal role should be in the delivery of public servcies:

   a) Whether direct federal involvement is necessary to guarantee some minimally acceptable level of services, and

   b) Whether certain national policy objectives would otherwise not be addressed.

2) Should there be a uniform definition of chronic disability?

3) Joseph Bevilacqua (24) has asked whether "functional realignment" away from population alignment is feasible? To Bevilacqua, "functional programming" asks the relationship of mental retardation residential costs to child delinquent residential costs, as an example.

4) Bevilacqua also asks whether there is a "core" of services, a "foundation of essential services," on which the continuum can be based and on which a coalition of interest groups can agree upon? Can "mini-systems" targeted to subpopulations be developed within the context of a "core" of services and based on "functional" activities?

5) As unemployment rises, as public budgets contract, and as the potential local economic impact of institutional reductions and closings are predicted, there will be increased protection of the institutional modality, particularly by public employee unions.

6) Although the 1981 Budget Reconciliation Act created seven new human services block grants, states will need to create structures which link the block grant programs administratively.

The National Association of State Mental Retardation Program Directors (25), President's Committee on Employment of the Handicapped (26), and General Accounting Office (27) have each documented the "absence of a national strategy or management system," the "lack of a clear set of overarching principles," and the lack of "a rudder to guide." This federal policy vacuum remains today. The instability of most federal human services programs combined with this policy vacuum creates an environment which seriously questions whether a continuum of care is likely in the decade of the 1980's.

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Other Resources: The UCPA Washington office publishes a monthly newsletter, Word From Washington, and a series of analytical papers, Word From Washington Analysis. These, as well as significant staff speech texts, are listed in the UCPA Materials List, 1982-1983 which is available by writing the Public Relations Department, UCPA, 66 East 34th Street, New York, NY 10016.

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